

“Connecting Helps Us Heal”: Using the Arts and Culture to Decolonize Research with HIV-Positive Aboriginal Women

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Visioning Health: Indigenous Issues, Indigenous Methodologies

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CHANGING THE COURSE OF THE
HIV PREVENTION, ENGAGEMENT AND
TREATMENT CASCADE

“Connecting Helps Us Heal”: Using the Arts and Culture to Decolonize Research with HIV-Positive Aboriginal Women



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MT, 1968 – 2012

Stacy Lee Bluebird, 1972 - 2012

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Kecia Larkin for coining the acronym **PAW** (Positive Aboriginal Women). This self-identification is important because “it imparts a dual meaning to being ‘positive’ and breaks down a first barrier in how Aboriginal women are portrayed by utilizing an assets-model approach” (EONS: 5 Year Strategy for Aboriginal Women and HIV, CAAN 2010).

Our partners, families and others who support us in our work and keep the home fires burning.

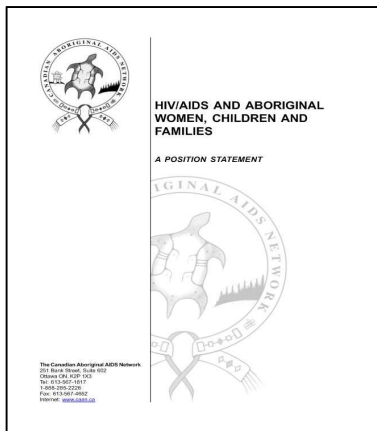
Our funders for making this work possible:



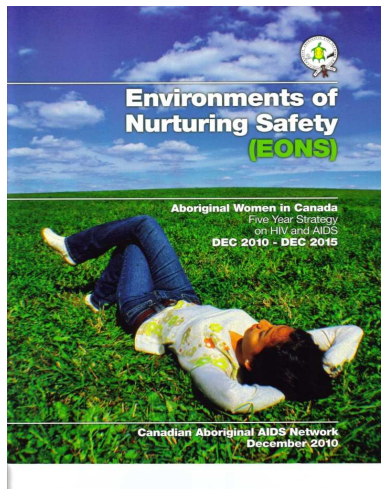
Presentation Overview

- Overview of *Visioning Health: PAW Perspectives on Health, Culture and Gender*
 - Why, How, Who, What
- Focus on what co-researchers said about their experience
- Leave you with some final thoughts on using the arts to decolonize research with PAW

Why Visioning Health?



- PAW / Aboriginal women as priority population
- “Startling lack of culturally-informed, gender-specific HIV care, treatment and support for Aboriginal women and girls” (CAAN, 2004)
- Predominance of deficit-model/illness-based/pathogenic research (*including resilience research*)
- Little research on what it means to be ‘healthy’ in context of living with HIV/AIDS for Aboriginal women



Goals and Objectives

- 1) Create space / opportunity for PAW to tell a different kind of story
- 2) Meaningfully engage PAW in arts-informed and culturally grounded research that would create new knowledge & knowledge products that were strengths-based, culturally-relevant and gender-specific
- 3) Hoped that women might gain some insight into their own strengths and assets and be inspired to build on those toward their vision of health and healthy communities

Guiding Principles

- In all community approaches, *process* – that is, methodology and method – is highly important. In many projects process is far more important than the outcome. Processes are expected to be respectful, to enable people, to heal and to educate. They are expected to lead one small step further towards self-determination (Tuhiwai Smith, 1999, pp. 127-128)
- The *way* researchers acquire knowledge in indigenous communities may be as critical for eliminating health disparities as the actual knowledge that is gained about a particular health problem (Cochrane et al. 2008, p.22)

Project Design

- Decolonizing / Indigenous Methodologies
 - OCAP / Capacity-bridging / CBPR
 - Arts-informed / Culturally grounded
 - Health-focused / Strength-based
 - Ceremony / Circle
- Women-Centred/GIPA
 - Safe spaces / non-judgement
 - Flexible / responsive
- Pop Health Framework
 - Broader SDoH
 - Social Ecological Model



Research Questions

- What does it mean to be 'healthy' as a PAW?
- What are the strengths and assets that help to create, support or maintain 'health' for PAW?
- What is the role of 'culture' in creating, supporting or maintaining health?
- What is the role of 'gender' and its intersections with other SDoH in creating, supporting or maintaining health?
- What are the policy and practice implications of our work?

Strategy of Inquiry

TO: 6mths = 50+ hrs



1. Group Recruitment
2. Group Orientation, Ground Rules & Preferences
3. Group Photo Training & Fieldtrip
4. **10** Bi-Weekly Group Meetings (In-Person)
5. **3** FG discussion
6. Photo Exhibition

Skype: 3mths = 50+ hrs



1. Group Recruitment
2. Group Orientation, Ground Rules & Preferences
3. Group Photo Training & Fieldtrip
4. **9** Weekly Group Meetings (Skype)
5. **3** FG discussions

MTL: 4days = 50+ hrs



1. Group Recruitment
2. Group Orientation, Ground Rules & Preferences
3. Drum-Making Workshop & Traditional Teachings
4. Drum Decorating Workshop, Songs & Traditional Teachings
5. **3** FG Discussions
5. Drum Awakening Ceremony, Traditional Teachings

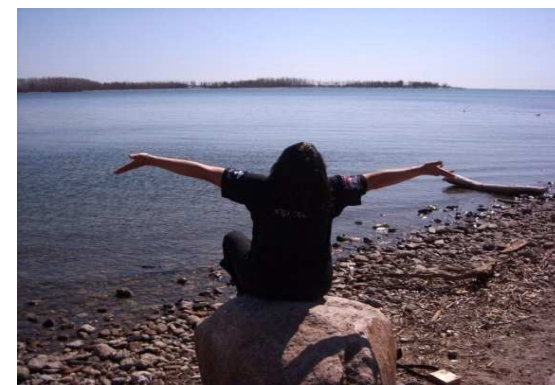
All Groups Mtg to Share, Compare, **Analyze**, Recommend (1.5 days)
Community-engaged KTE = 31 Co-presentations & 17 Photo Exhibitions (4 VH Lodges)

Who Participated? (N=13)

- First Nations and Inuit women*
- Across 4 provinces and 6 cities/towns/reserves
- Urban and reserve
- Newly diagnosed to long-term survivors
- Late 20s to late 50s
- Straight, trans and two-spirit
- Different places in their lives ('stable' lives to street-involved and everything in between)
- Mothers, grandmothers, sisters, aunties, artists, & advocates

What Does 'Health' Mean for PAW?

- “Connecting Helps Us Heal”
 - Health for PAW is fundamentally about **connecting and feeling connected** – to themselves, to their peers/families, to their communities, to their culture, to the land and environment, to the Creator/cosmos



What Supports PAWs Health?

- “Creator Gives Us What We Need”: Culture, Tradition & Spirituality
- “You Don’t Get To Tell Me Who I Am!”: Reclaiming Voice and Identity
- “We’re Still Here!”: Resistance, Resilience and Restoration
- “I’m HIV+...So Fucking What!”: Stigma, Discrimination and Need for Safe Spaces
- “Shaped By My Environment”: Understanding the Influence of Early/Life Experiences
- “Water is Women’s Responsibility”: Culture, Gender and Health
- “Find[ing] Strength and Safety”: Health and Healing Through Nature

What Did PAW Say About VH?

- VH was “life-changing”, “life-giving”, “life-saving”.
- VH was “a healing journey”, “good medicine”, “inner healing”, “a powerful journey”, “healing in lots of ways”.
- VH helped PAW “connect” – with self, others, community and culture

Connecting with Self



“Connecting the dots of my life”

Connecting with Others



“I don’t feel so alone anymore”

Connecting with Community



“I want to help people like me”

Connecting with Culture



“Awakening of identity”

Concluding Thoughts

If 'health' for PAW = "feeling connected",
and, participating in VH = "feeling connected",

Then, participating in VH = better 'health'!



Lessons Learned

- Focused on 'process' = always putting needs of women ahead of needs of research
- Decolonizing methodology that created conditions for women to 'own' the research and to empower themselves
 - OCAP / GIPA / Meaningful engagement
- Arts-informed, culturally grounded, and 'group' research processes that helped women 'connect' to themselves and others on deeper, richer and more personal level



Miiquetch /Thank You